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Daily Hassles Reported by Chronic Fatigue Syndrome and Fibromyalgia Patients in Tertiary Care: A Controlled Quantitative and Qualitative Study

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Key Words

Chronic fatigue syndrome · Fibromyalgia · Daily hassles · Stress · Anxiety · Depression · Psychotherapy

Abstract

Background: This study aimed at providing insight in the frequency, emotional impact and nature of daily hassles, experienced by patients suffering from chronic fatigue syndrome (CFS) and/or fibromyalgia (FM), compared with patients with a chronic organic disease. **Methods:** One hundred and seventy-seven CFS/FM patients, 26 multiple sclerosis (MS) and 26 rheumatoid arthritis (RA) patients were investigated within 2–6 months after diagnosis. All patients completed a self-report questionnaire assessing daily hassles and associated distress, a visual analogue scale assessing fatigue and pain and a depression and anxiety questionnaire. **Results:** CFS/FM patients show a higher frequency of hassles, higher emotional impact and higher fatigue, pain, depression and anxiety levels compared with MS/RA patients. Three hassle themes dominate in the CFS/FM group: dissatisfaction

with oneself, insecurity and a lack of social recognition. In contrast, hassles reported by MS/RA patients show a much larger diversity and are not focused on person-dependent problems. **Conclusions:** Patients recently diagnosed as suffering from CFS and/or FM are highly preoccupied and distressed by daily hassles that have a severe impact on their self-image, as well as their personal, social and professional functioning. An optimal therapeutic approach of CFS and FM should take account of this heavy psychosocial burden, which might refer to core themes of these patients' illness experience.

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Introduction

Chronic fatigue syndrome (CFS) and fibromyalgia (FM) still remain ill-defined and badly understood conditions, characterised by physical and mental fatigue, diffuse muscle and joint pain, effort intolerance, headache, sleep disturbances and signs of mild immunological dysfunction [1, 2]. Symptoms and non-symptomatic charac-

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teristics of both illnesses are thought to be largely overlapping [3–5], although their pathophysiological basis may differ [6].

It has been hypothesised, from a psychological as well as from a neurobiological point of view, that the syndromes may be ‘stress related’ [7–9]. This hypothesis is, on the one hand, based on the fact that negative life events (often combined with a viral infection or a physical trauma) [10–13], victimisation experiences [14, 15] and the mental or physical stress of an overactive lifestyle [16, 17] have been found to be frequently associated with the development of CFS/FM. On the other hand, there is ample evidence that CFS and FM patients are confronted with severe psychosocial stress related to coping and adaptation problems, a lack of comprehension by the environment and uncertainties surrounding the nature and prognosis of their condition [18–21].

Interestingly, negative life events have been found to exacerbate CFS symptoms [22] and worsen the prognosis of FM [23]. This suggests that antecedent psychosocial or physical stress could increase vulnerability for subsequent (reactive or other) stressors, which in turn could influence disease activity and/or disability [7–9].

Furthermore, neurobiological investigations have repeatedly shown hypothalamo-pituitary-adrenal axis functioning to be perturbed in CFS as well as FM, implying a lack of reactivity of this axis and resulting in decreased cortisol secretion [24–26].

Finally, psychosocial stress may not only be linked with major life events, but with minor events as well. Such ‘daily hassles’ or ‘everyday problems’ can cause considerable worry and concern and, by their chronic and accumulating character, may be as stressful as a major negative event [27]. In FM patients, higher levels of daily hassles have been found compared with rheumatoid arthritis (RA) patients and pain-free controls [28, 29]. To the best of our knowledge, however, this type of chronic life stress has not yet been empirically investigated in CFS.

In the present study, we evaluated the frequency, emotional impact and nature of daily hassles, as well as fatigue, pain, depression and anxiety experienced by recently diagnosed CFS and FM patients. Data of the CFS/FM group were compared with those of a control group consisting of recently diagnosed multiple sclerosis (MS) and RA patients, i.e., two well-defined organic conditions that are characterised by chronic fatigue and pain as well. Frequency and emotional impact of hassles were additionally calculated for women and men.

Materials and Methods

Subjects and Setting

Participants were recruited from a multidisciplinary clinic for patients with chronic fatigue and/or widespread pain belonging to the departments of General Internal Medicine and Rheumatology of the University Hospital Leuven, Belgium.

The experimental group consisted of 177 consecutive patients (149 women and 28 men) meeting the Fukuda criteria for CFS [30] and/or the ACR criteria for FM [31]. One hundred and ten patients received ‘CFS’ as a primary diagnosis, while 67 were diagnosed as suffering from ‘FM’; however, since about 80% of the patients fulfilled both sets of diagnostic criteria, we decided to consider the two groups together.

The control group consisted of 26 MS and 26 RA patients (41 women and 11 men), consulting at the National Multiple Sclerosis Clinic and the Rheumatology Department of our hospital, respectively. All control patients complained of fatigue and pain, but showed no visible signs of disease. The latter inclusion criterion was intended to make the experimental and the control group as comparable as possible with regard to physical functioning, and avoid differences in social contacts due to overt disease characteristics.

CFS/FM patients were investigated during a consultation that took place within 2 months after the diagnosis was made. MS/RA patients were investigated within 6 months after diagnosis. They all filled in a visual analogue scale measuring fatigue and pain, as well as the ‘Everyday Problem Checklist’ (EPCL), the Beck Depression Inventory (BDI) and the State Trait Anxiety Inventory (STAI) self-report questionnaires (see below).

Mean symptom duration was assessed via the patients’ medical records. It was 35.5 months in CFS/FM patients ($SD = 44.1$) and 50.4 months in MS/RA patients ($SD = 49.1$), which is significantly different, $t(227) = 2.09$; $p = 0.038$. Patient characteristics are summarised in table 1.

Psychometric Instruments

Daily hassles were assessed using the EPCL, a Dutch self-report questionnaire which has been proved to be sufficiently reliable and valid [32]. The questionnaire, containing 114 items, focuses on a large diversity of common life problems, with regard to personal functioning, family life, social life, housing conditions, finances, professional life, confrontations, social developments and general stress situations. The questions have to be answered by ‘yes’ or ‘no’, and the associated distress (or emotional impact) can be indicated on a scale from 0 to 3.

The EPCL questionnaire provides scores on three *frequency* subscales, i.e., general frequency (FREQ), frequency of person-dependent problems (DEP-FREQ) and frequency of person-independent problems (INDEP-FREQ); in the same vein, there are three *total distress* scores (TOT, DEP-TOT and INDEP-TOT), and three *mean intensity per item* scores (INT, DEP-INT and INDEP-INT).

Depression was assessed by the BDI [33], and anxiety by the STAI [34].

Data Analysis

Descriptive statistics, frequency analyses and statistical tests were performed using SAS [35]. For the comparison of means between the two groups, separate-variance and pooled-variance Student *t* tests were performed. For the tests of association between categorical variables, χ^2 tests were used and Cramér contingency coefficients (*C*)

Table 1. Characteristics of the CFS/FM and MS/RA patient groups

	CFS/FM	MS/RA	p
Number of patients	177	52	
Gender (m/f), %	16/84	21/79	n.s.
Mean age, years	37.8 (8.6)	40.4 (9.4)	n.s.
Unemployed, %	14	8	n.s.
Housewife, %	19	13	n.s.
Blue collar, %	30	27	n.s.
White collar, %	37	52	n.s.
Single/with partner, %	18/82	21/79	n.s.
Having children (yes/no), %	68/32	62/38	n.s.
Mean duration of symptoms, months	35.5 (44.1)	50.4 (49.1)	<0.05

The figures in parentheses are SD.

were calculated [36]. In order to obtain optimal statistical power for answering our main research question, the data for the MS and RA group were pooled. Three-group analyses of variance confirmed that there were no differences between the MS and RA group on any of the parameters.

Results

Quantitative Group Comparisons

The CFS/FM group significantly differs from the MS/RA group on nearly all EPCL subscales. As can be seen in table 2, CFS/FM patients report a statistically significantly larger number of daily hassles in general, as well as for the person-dependent and the person-independent hassles separately ($p < 0.05$). For each of these variables, the accompanying total distress and mean intensity per item scores are also significantly higher for the CFS/FM patients, with the exception of the mean intensity per item scores for the person-independent hassles where there was no statistically significant difference between CFS/FM and MS/RA patients [$t(227) = 0.58$, $p = 0.5625$ two-tailed].

With regard to somatic symptoms, fatigue and pain show higher mean levels in CFS/FM patients than in MS/RA patients [$t(227) = 11.85$, $p < 0.0001$ and $t(227) = 6.49$, $p < 0.0001$, respectively] (table 3).

With regard to affective symptoms, CFS/FM patients are more depressed [$t(227) = 6.19$, $p < 0.0001$] and show more state anxiety [$t(227) = 4.39$, $p < 0.0001$] and trait anxiety [$t(227) = 4.42$, $p < 0.0001$] than MS/RA patients (table 3).

Table 2. Comparison of mean EPCL subscale scores between CFS/FM and MS/RA patients

	CFS/FM	MS/RA	t
FREQ mean	28.4 (16.7)	20.7 (14.7)	2.97**
DEP-FREQ mean	7.1 (4.6)	5.0 (4.3)	3.04**
INDEP-FREQ mean	5.0 (3.3)	4.0 (2.4)	2.04*
TOT mean	50.3 (36.9)	29.3 (25.5)	4.67***
DEP-TOT mean	13.1 (10.0)	6.8 (7.2)	4.23***
INDEP-TOT mean	8.2 (7.1)	5.9 (4.4)	2.79**
INT mean	1.7 (0.6)	1.4 (0.5)	3.60***
DEP-INT mean	1.7 (0.8)	1.2 (0.8)	4.12***
INDEP-INT mean	1.5 (0.8)	1.4 (0.7)	0.58 n.s.

The figures in parentheses are SD.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 3. Comparison of mean scores of fatigue, pain and affective symptoms between CFS/FM and MS/RA patients

	CFS/FM	MS/RA	t
Fatigue mean	7.5 (1.1)	5.3 (1.6)	11.85****
Pain mean	5.7 (2.7)	3.0 (2.4)	6.49****
BDI mean	18.0 (8.8)	9.6 (7.9)	6.19****
STAI-State mean	47.0 (13.4)	37.6 (14.1)	4.39****
STAI-Trait mean	47.6 (10.8)	40.1 (10.6)	4.42****

The figures in parentheses are SD.

**** $p < 0.0001$.

It can additionally be mentioned that female CFS/FM patients score higher than male patients on nearly all EPCL subscales ($p < 0.05$), with the exception of the mean intensity per item subscales (table 4). This is in accordance with similar sex differences found in a healthy population and other clinical populations [32].

Qualitative Group Comparisons

Looking into more detail to FREQ scores of the EPCL scale, the following person-dependent items are mentioned by more than 50% of the CFS/FM patients: 'you failed to accomplish tasks that you thought you were capable of doing', 'your sleep was disturbed', 'you were in a state of insecurity', 'certain people did not consider your feelings' and 'something brought back unpleasant memories'.

Table 4. Comparison of mean EPCL subscale scores between female and male CFS/FM patients

	CFS/FM		<i>t</i>
	females n = 149	males n = 28	
FREQ mean	29.8 (17.3)	20.9 (10.6)	2.63**
DEP-FREQ mean	7.5 (4.8)	5.0 (3.0)	2.66**
INDEP-FREQ mean	5.2 (3.5)	3.7 (1.8)	2.21*
TOT mean	53.7 (38.1)	32.9 (23.4)	2.79**
DEP-TOT mean	13.9 (10.4)	8.9 (6.3)	2.48*
INDEP-TOT mean	8.8 (7.5)	5.0 (3.5)	2.62**
INT mean	1.7 (0.6)	1.5 (0.5)	1.66 n.s.
DEP-INT mean	1.8 (0.8)	1.5 (0.8)	1.82 n.s.
INDEP-INT mean	1.5 (0.8)	1.3 (0.7)	1.24 n.s.

The figures in parentheses are SD.

* $p < 0.05$, ** $p < 0.01$.

Table 5. Qualitative comparisons of total distress scores between CFS/FM and MS/RA patients

TOT personal functioning	CFS/FM > MS/RA	($p = 0.0005$)
social life	CFS/FM > MS/RA	($p = 0.0008$)
professional life	CFS/FM > MS/RA	($p = 0.0009$)
confrontations	CFS/FM > MS/RA	($p = 0.0071$)
general stress	CFS/FM > MS/RA	($p = 0.01$)
social developments	MS/RA > CFS/FM	($p = 0.0001$)

Table 6. Correlations between duration of symptoms and EPCL subscales in CFS/FM and MS/RA patients

	CFS/FM	MS/RA
Duration (<12 vs. >12 months)	~ no EPCL-subscales	~ FREQ**** ~ DEP-FREQ*** ~ TOT* ~ DEP-TOT*
~ = Correlates with; * $p < 0.05$, *** $p < 0.001$, **** $p < 0.0001$.		

In contrast, among MS/RA patients, only one person-independent item is mentioned by more than 50%: 'certain items in the news concerned you', whereas all other items are mentioned at much lower frequencies.

Comparing TOT scores of CFS/FM patients with those of the control group (table 5), CFS/FM patients show higher distress for personal functioning [$t(227) = 3.54$; $p = 0.0005$], characterised by the following items: 'you failed to accomplish tasks that you thought you were capable of doing' [$\chi^2(4) = 19.93$; $C = 0.30$; $p = 0.0005$], 'you were in a state of insecurity' [$\chi^2(4) = 17.05$; $C = 0.27$; $p = 0.0019$], 'you could not be yourself' [$\chi^2(3) = 12.73$; $C = 0.24$; $p = 0.0053$] and 'you were dissatisfied with your looks' [$\chi^2(4) = 10.92$; $C = 0.22$; $p = 0.028$].

CFS/FM patients are also more distressed in social life [$t(120.8) = 3.44$; $p = 0.0008$], illustrated by: 'you had to bid farewell to a good colleague, friend or acquaintance due to a change of job, a move or a trip' [$\chi^2(4) = 14.60$; $C = 0.25$; $p = 0.0056$], 'people around you did not respect you' [$\chi^2(4) = 11.62$; $C = 0.23$; $p = 0.020$] and 'certain people did not consider your feelings' [$\chi^2(4) = 9.67$; $C = 0.21$; $p = 0.046$].

Furthermore, CFS/FM patients experience more distress in professional life [$t(118.3) = 3.42$; $p = 0.0009$], illustrated by: 'you were not able to complete a certain task to your satisfaction' [$\chi^2(4) = 11.252$; $C = 0.22$; $p = 0.021$], in confrontations [$t(125.8) = 2.74$; $p = 0.0071$], illustrated by: 'you were confronted with preconceptions or discrimination' [$\chi^2(3) = 8.02$; $C = 0.22$; $p = 0.021$], and in general stress situations [$t(119.7) = 3.08$; $p = 0.01$], illustrated by: 'certain developments did not proceed according to plan' [$\chi^2(4) = 10.43$; $C = 0.21$; $p = 0.034$].

It may be concluded that the majority of CFS/FM patients feel deeply frustrated and insecure about their own functioning as well as their social and professional relationships. In contrast, MS/RA patients are only significantly more distressed by social developments [$t(227) = 3.99$; $p = 0.0001$], illustrated by person-independent items such as: 'you did not approve of certain political developments or decisions' [$\chi^2(4) = 23.32$; $C = 0.34$; $p = 0.00001$] and 'certain events in the news concerned you' [$\chi^2(4) = 18.64$; $C = 0.29$; $p = 0.0009$].

Correlations between Daily Hassles and Duration of Symptoms

In CFS/FM patients, the subgroup of CFS/FM patients with symptoms existing less than 12 months and the subgroup with symptoms existing for a longer period do not show any difference on the EPCL subscales. In contrast, MS/RA patients with a longer duration of symptoms (12 months and more) show a higher FREQ, $t(38.3) = 4.51$,

$p = 0.0001$ and DEP-FREQ, $t(40.9) = 3.71$, $p = 0.0006$, as well as a higher TOT, $t(35.9) = 3.55$, $p = 0.0011$ and DEP-TOT $t(30.9) = 2.81$, $p = 0.0086$ (table 6).

Discussion

The main goal of the present study was to obtain insight into the frequency, emotional impact and nature of daily hassles in recently diagnosed CFS and FM patients, compared with patients with a recently diagnosed chronic organic disease.

It was found that CFS/FM patients struggle with significantly more hassles than the control group. CFS/FM patients' hassles are also associated with a higher degree of emotional distress. Additionally, female CFS/FM patients report more hassles than men and seem, to a certain degree, also more emotionally affected.

Moreover, the nature of CFS/FM patients' hassles is clearly different from those of the control group, i.e., they are much more person-dependent and mainly refer to 3 major themes: (1) dissatisfaction with oneself, (2) feelings of insecurity and (3) insufficient social recognition. In contrast, MS/RA patients mention hassles that are mainly person independent, more heterogeneous and comparable with the norm group of healthy subjects [32], with the exception of sleep disturbances. In fact, the triangle 'dissatisfaction – insecurity – lack of social recognition' is not present at all in MS/RA patients.

Finally, the frequency of daily hassles and associated distress increase with the duration of symptoms in MS/RA patients, while this increase is remarkably absent in CFS/FM patients.

Trying to interpret the above results, two possibilities arise. First, it could be that CFS/FM patients are more preoccupied with hassles related to personal deficiency because they have higher levels of fatigue and pain. Also, given the uncertainties surrounding their illness, CFS/FM patients could be more focused on hassles related to insecurity. However, the control group, despite experiencing fatigue and pain as well, and being confronted with – even greater – uncertainty about future loss of function, seems far less impressed by the person-dependent problems that are in the midst of CFS/FM patients' preoccupations.

Furthermore, CFS/FM patients' worries about social recognition could refer to their feeling 'not being taken seriously'. Many CFS and FM patients suffer indeed from incomprehension and dismissive reactions from their environment, while this is usually not the case in MS/RA patients. Nonetheless, symptoms of MS/RA may long be

similarly vague, exposing at least some of them to disbelief as well.

A second interpretation, therefore, could be that CFS/FM patients – in contrast to MS/RA patients – fail to adapt to their daily worries and concerns because the latter might refer to the core of their illness experience. CFS/FM patients' preoccupations may, notably, reflect deep disappointment and frustration about their failed strivings for physical or mental achievement, as well as approval from others. Such strivings – which have been described as a central theme in the illness narratives of CFS/FM patients [37] – may be psychodynamically linked to personality factors, such as a vulnerable self-esteem [38–40], narcissistic or perfectionistic tendencies [41, 42] and, not uncommonly, early victimisation experiences [14, 15].

The manifestly higher levels of depression and anxiety in the CFS/FM group could fit into both interpretations. On the other hand, support for the second interpretation is provided by the fact that all CFS/FM patients show a similar amount of hassles and distress, irrespective of the duration of symptoms. In contrast, MS/RA patients with a longer duration of symptoms report more (and particularly more person-dependent) hassles and distress, suggesting that the latter may be linked to a deterioration of the illness. However, our results do not allow causal inferences, since the duration of symptoms largely goes beyond the period covered by the EPCL questionnaire.

In any case, these findings may have important therapeutic implications. They notably suggest that treatment approaches should pay sufficient attention to CFS/FM patients' struggle with a multitude of daily hassles that severely impact their self-image and lay a heavy burden on their personal, professional and social functioning. This would imply that psycho-educational, cognitive-behavioural and 'graded activity' treatments [43–45] should in many cases be complemented with experiential or psychodynamically-oriented therapeutic strategies [46, 47] – not only to support the patients' coping with symptoms and functional limitations, but also to help them adapt to changing ambitions and life goals.

Limitations

The results of this study should be interpreted within the context of several methodological limitations.

First, all CFS and FM patients were seen in tertiary care, implying a selection bias that requires some caution in generalising the results to a broader patient population.

Second, despite the fact that all CFS/FM and MS/RA in our study were characterised by similar symptoms and lacked visible signs of disease, the associated disability in the two groups might have been different. Whether this could have influenced our results cannot be determined, since no disability measures were used.

Third, both groups were not investigated at exactly the same time after diagnosis. This could have biased our results because both groups might have been in a different stage of coping and adaptation (i.e., after 2 months, the patients could be in an emotional crisis, whereas after 6 months, this crisis might be less pronounced).

Finally, the differences in mean illness duration between the groups (35.5 vs. 50.4 months) and, as mentioned in the previous section, the higher levels of fatigue, pain, depression and anxiety in the CFS/FM group could be considered confounding factors as well.

Conclusions

Within the above limitations, this study demonstrates that recently diagnosed CFS or FM patients are overwhelmed by person-dependent daily hassles and emotional distress, focused on dissatisfaction with themselves, feelings of insecurity and lack of social recognition. Although such experiences and concerns might be linked with personality factors increasing vulnerability to CFS and FM, prospective research is necessary to disentangle the complex cause/effect interactions between stress, symptoms and disability in these patients. Treatment should, in any case, pay sufficient attention to the severe personal, social and professional burden these patients are confronted with, to help them cope and facilitate long-term adaptation.

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